

RESEARCH COMMUNICATION

Complementary and Alternative Medicine Use among Cancer Patients at the End of Life: Korean National Study

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Abstract

Objectives: To investigate in depth the use of complementary and alternative medicines (CAMs) by cancer patients at the end-of-life (EOL) and how they communicate with physicians about them. **Design and location:** In 17 hospitals in Korea between January and December 2004 we identified 4,042 families of cancer patients. **Results:** The prevalence of CAM use among cancer patients at the EOL was 37.0%, and 93.1% had used pharmacologic types of agents. The most frequent motive for CAM use was the recommendation of friends or a close relative (53.4%) or a physician (1.6%). Only 42.5% discussed CAM use with their physicians. Satisfaction with CAMS was recalled for 37.1%. The most common reason given for that satisfaction was improvement of emotional or physical well-being, while ineffectiveness was the most common reason given for dissatisfaction. The average cost of CAM during the last month of life was \$US 900. CAM use was associated with longer disease periods, primary cancers other than liver, biliary, and pancreatic, and need of support from physicians or religion. **Conclusions:** CAM use among cancer patients at the EOL was common, not discussed with physicians, and associated with expectation of cure. Expectations were generally unmet while the treatments were a financial burden. Further studies evaluating the effects of CAM at the EOL and factors that enhance communication with the physician are needed.

Key words: Complementary and alternative medicine - end of life - Korean cancer patients

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Introduction

The use of complementary and alternative medicine (CAM) is widespread among cancer patients (Ang-Lee et al., 2001; Richardson et al., 2000), but prevalence, usage patterns, rationale for use, and user characteristics vary geographically (Hyodo et al., 2005; WHO, 2007). Some CAMs of demonstrated effectiveness are used as an adjunct to conventional medical treatments in a holistic approach to cancer care termed integrative medicine (Tas et al., 2005), although the level of integration and the quality of care vary among individual cancer centers (Robotin and Penman, 2006).

At the end of life (EOL), mental and emotional

problems and disease symptoms, which become increasingly burdensome (Richardson et al., 2004; Tilden et al., 2004), are often poorly addressed by conventional medicine (Steinhauser et al., 2000), and palliative care is needed to improve quality of life (Lafferty et al., 2006). Decisions that lead to the use of CAMs are often seen as pragmatic and a last resort when mainstream medicine has nothing left to offer (Vitetta and Sali, 2006). Despite its widespread use, the scientific evidence of effectiveness of CAM is associated with a high level of uncertainty (Schraub, 2000) and most patients and experts see CAM's role confined to supportive care (Downer et al., 1994). Most patients, however, do not discuss CAM with their physicians (Richardson et al.,

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Table 1. Characteristics of Responders and Non-responders Before and After Adjustment

		Un-weighted			Weighted†		
		Responders (n=1,662,41.1%)	Non-responders (n=2,380,58.9%)	P	Responders (n=3,460, 50.0%)	non-responder (n=3,464, 50.0%)	P
Sex	Male	42.3	57.7	0.049*	49.9	50.1	0.89
	Female	39.1	60.9		50.1	49.9	
Age (years, mean (SD))		62.2	60.0	<.001*	61.2	61.2	0.79
		-13.8	-14.5		-22.4	-19.0	
Marital status	Couple	38.9	61.1	<0.01*	50.0	50.0	0.97
	Single	46.8	53.2		49.9	50.1	
Education level	£ Middle school	45.9	54.1	0.028*	50.0	50.0	0.98
	High school	40.9	59.1		49.8	50.2	
	≥ College	45.0	55.0		50.2	49.8	
Place of Residence	Rural	43.5	56.5	0.004*	50.0	50.0	0.94
	Urban	60.9	39.1		49.9	50.1	
Health Insurance	Private	43.0	57.0	0.174	50.0	50.0	0.99
	Medicaid	47.0	53.0		50.0	50.0	
Household income, (\$US/month)	< 1,000	40.2	59.8	0.034*	49.9	50.1	0.10
	1,000-2,499	41.8	58.2		49.9	50.1	
	2,500-4,999	45.8	54.2		50.0	50.0	
	≥ 5,000	45.7	54.3		50.2	49.8	
Primary cancer site	Liver	57.5	42.5	0.270	49.9	50.1	1
	Oral/Esophagus.	58.1	41.8		49.8	50.2	
	Stomach	60.8	39.2		50.0	50.0	
	Intestine	59.7	40.3		49.8	50.2	
	Gallbladder	56.6	43.4		49.8	50.2	
	Pancreas	51.2	48.8		49.8	50.2	
	Lung	58.7	41.3		50.0	50.0	
	Breast	61.5	38.5		50.6	49.4	
	Uterus	66.7	33.3		49.8	50.2	
	Others	59.7	40.3		50.5	49.5	

CAM, complementary and alternative medicine *Statistically significant: P < 0.05 †Weighted with ITPW estimator adjusted with sex, age, marital status, education level, place of residence, insurance status, household income, and primary cancer site

2004) and to our knowledge, few studies have examined CAM use at EOL in depth (Lafferty et al., 2006). Here we examine CAM use patterns, communication of its use with physicians, and factors contributing its use among Korean cancer patients at EOL.

Materials and Methods

Patients

Decedents were aged ≥ 18 yr and had died of cancer in the general ward, emergency room, intensive care unit, or hospice unit in any of 17 Koran hospitals between January and December of 2004. The institutional review boards of all 17 hospitals approved the study questionnaire and protocol.

We reviewed medical records and obtained family telephone numbers for 4,042 patients. We attempted to contact all families, repeating calls 3 or more times if necessary. Family subject eligibility included being aged ≥ 18 yr, having had a significant relationship with the decedent, and being the main caregiver or familiar with the decedent’s care. From June to July in 2005, we interviewed one respondent per decedent by telephone, obtained consent, and asked about the decedent’s use of CAM. Research assistants conducted all interviews after

receiving intensive training in telephone survey methods for the structured questionnaire. Supervisors listened to all interviewers and corrected mistakes. Although the study protocol included a provision that in the event of any serious problems in the execution of a questionnaire, the data for that particular subject would be discarded, such a situation did not arise.

Questionnaire

The first page of the questionnaire stated the National Center of Complementary Alternative Medicine (NCCAM) definition of CAM and its 5 categories. The questionnaire covered background and sociodemographic factors of the patient and caregiver (sex, age, marital status, educational level, place of residence, insurance status, monthly income, diagnosis, disease period length, need of consultation about further care, need of symptom control, need of financial support, need of psychological counsel, need of religious support, and need of voluntary services) and CAM use (type and cost of CAM, motive for starting CAM, satisfaction with CAM used, reason for satisfaction or dissatisfaction, communication with physician re CAM, response of physician, reason for not consulting physician).

Table 2. Types of CAM Used by Cancer Patients at EOL

Type of CAM	Un-weighted (n=604, 36.3%)		Weighted** (n=1,281, 37.0%)	
	No. of patients	%	No. of patients	%
Alternative medical system	126	20.9	253	19.8
Oriental herbal medicine	109	18.1	221	17.3
Acupuncture	30	5.0	61	4.8
Ayurveda	3	0.5	6	0.5
Mind-body intervention	1	0.17	2	0.06
Prayer	1	0.17	2	0.06
Biologically based therapies	512	84.8	1096	85.5
Herbs	20	3.3	45	45.7
Vitamins	12	2.0	26	2.1
Dietary supplements	345	58.6	777	60.7
Vegetable juice	197	32.6	402	32.8
Mushrooms	345	57.1	723	56.4
Ginseng	176	29.1	372	29.1
Rice and cereals	73	12.1	161	12.6
Soybean	5	0.8	11	0.9
Tangle	1	0.2	2	0.2
Chitosan	2	0.3	4	0.4
Shark cartilage	7	1.2	16	1.1
Grape juice	3	0.5	7	0.6
Aloe	1	0.2	2	0.2
Safflower seed oil	1	0.2	2	0.2
Root bark of various araliaceous shrubs	1	0.2	2	0.2
Hydrotherapy	1	0.2	2	0.2
Massage	3	0.5	6	0.5
Manipulative and body-based methods				
Gi-gong	5	0.8	11	0.9
Energy therapies				
Others	97	16.1	209	16.3
Type				
Pharmacologic type	560	92.7	1192	93.1
non-pharmacologic type	39	8.8	81	8.4

CAM, complementary and alternative medicine; EOL, end of life * Weighted with the ITPW estimator adjusted with sex, age, marital status, education level, place of residence, insurance status, household income, and primary cancer site

Statistical Analysis

We performed all analyses with data weighted to the population of eligible participants. To adjust for observable differences between participants and non-participants, we used the inverse probability of treatment weighting (IPTW) estimator⁴² with sex, age, marital status, education level, place of residence, insurance status, household income, and primary cancer site. The IPTW estimator uses as weights the inverse (estimated) propensity score for survey respondents and the inverse of 1 minus the propensity score for survey non-respondents. Thus, IPTW estimates a standardized population. These “adjustment” weights, often referred to as propensity scores, serve to create a weighted population. Propensity scores have two important features—they eliminate confounding by covariates, and they equalize the weighted population with the original reference population.

When we evaluated the balance of covariates in the weighted population, the IPTW model yielded no extreme odds ratios, indicating little sampling bias. We calculated weighted odds ratios (ORs) and 95% confidence intervals (CIs) for significant covariates in multiple logistic analyses. We used SAS software (version 9.1) for the analyses and considered a two-sided

P value < 0.01 significant.

Results

Study Population

We were not able to reach 1,643 (40.6%) of the decedents' families because of a changed telephone number or lost contact. Of the 2,399 subjects who were contacted, 737(30.7%) refused to participate or did not complete the interview, leaving 1,662 (69.3%, of 2,399; 41.1% of 4,042) participants. No statistically significant differences in socio-demographic or clinical characteristics between respondents and non-respondents after adjustment with the IPTW estimator were evident. The study included 3,460 participants weighted by the IPTW estimator (Table 1).

Types of CAM used

The IPTW estimator weighted CAM-use prevalence (37%) and unweighted CAM-use prevalence (36.6%) were similar (Table 2). Table 2 shows the frequency of use of the 5 types of CAM defined by NCCAM. The most frequently used CAMs were biologically based therapies (85.5%) and alternative medical systems (19.8%). Dietary supplements were the most frequently used

Table 3. Predictors of CAM Use*

		Odds ratio	Lower	Upper
Medical factors	Time since diagnosis	≤1yr	1	
		1-2yr	1.58	1.31 1.92
		≥2yr	1.71	1.43 2.04
	Primary cancer	Liver/biliary/pancreas		1
	Other	1.31	1.113	1.53
Needed support	Discuss with physician about EOL treatment	No	1	
		Yes	1.61	1.35 1.92
	Religion	No	1	
		Yes	1.27	1.09 1.47

CAM, complementary and alternative medicine *Calculated by stepwise logistic regression, adjusted for sex, age, marital status, education level, place of residence, insurance status, household income, patient's occupation, need of symptom management, financial support and psychological support and weighted with the ITPW estimator adjusted with sex, age, marital status, education level, place of residence, insurance status, household income, and primary cancer site

biologically based therapy (60.7%), with mushrooms leading the list (56.4%). Pharmacologic therapies (oriental herbal medicines and biological based therapies) were used with greater frequency (93.1%) than non-pharmacologic therapies (acupuncture, ayurveda, mind-body intervention, manipulation, and energy therapies) (8.4%).

Predictor of CAM use

In stepwise multivariate logistic regression analysis, IPTW estimator weighted results and unweighted results were similar (Table 3). CAM use was associated with a longer disease period, chemotherapy-responsive cancers, and a need for supportive care from physicians or religion.

Discussion

This is the first large nationwide study to broadly assess CAM use among cancer patients approaching the end of life. Results showed a high prevalence of CAM use but a low prevalence of consultation with physicians about that use.

The weighted prevalence of EOL CAM use (37%) was lower than that reported in the U.S. (53.7%) or Australia (64%) (Tilden et al., 2004). The overall prevalence of CAM use in cancer patients ranges from 7% to 98% (Navo et al., 2004; Swisher et al., 2002) with the Japanese rate (44.6%) being somewhat higher than ours. The broad range is due in part to different definitions of CAM, differences in the size and nature of the study population (Navo et al., 2004), and different geographic settings (Molassiotis et al., 2005).

The present study revealed different patterns of CAM use in Korea compared with Western countries. While few in our study sample had used nonpharmacologic CAMs, 35%-80% of Western cancer patients (not

necessarily at EOL) do use them (Navo et al., 2004). Non-pharmacological CAMs, such as spiritual practice, mind and body therapy, and homeopathy (Risberg et al., 2003) are more likely to involve a well-trained CAM practitioner and greater expense (WHO, 2007). Some non-pharmaceutical CAMs (acupuncture, massage, hypnotherapy, relaxation) show promise for palliative care, but there is insufficient evidence to recommend their widespread use (Pan et al., 2000). In the U.S., EOL CAM use seems to depend on sociocultural variables (Lafferty et al., 2006) and "fashion" trends (Morris et al., 2000). Populations throughout Africa, Asia, and Latin America meet their primary health care needs with traditional medicine. In addition to being accessible and affordable, traditional medicine is often part of a wider belief system and is considered integral to everyday life and well-being (Hyodo et al., 2005). Belief is also involved in CAM use. Many cancer patients hold hope that CAM can fight cancer directly (Molassiotis et al., 2005; Vitetta and Sali, 2006) or enhance the body's ability to fight cancer (Risberg et al., 2003; Sollner et al., 1998), helping them to live longer (Richardson et al., 2000). Such expectations, however, go unfulfilled, as they were in this study (Molassiotis et al., 2005; Sollner et al., 1998).

Our finding that only 37.1% of CAM users were satisfied with CAM is consistent with the findings of others (Spiegel et al., 1989). Although most (62.9%) patients in our study did not benefit from CAM, an Australian study reported that CAM could help control cancer symptoms and enhance QOL (Risberg et al., 1995).

Moreover, 2.9% of our study patients reported adverse effects, which is similar to the findings in Europe (4.4%) (Molassiotis et al., 2005) and the U.S. (6%) (McPherson and Addington-Hall, 2003). Despite their extensive use, there is a paucity of data available to indicate whether CAM practices are efficacious and safe (Spiegel et al., 1989; Risberg et al., 2003).

Most patients who use CAMs believe that they are "natural", equating that with "safe" and "health-promoting" (Sollner et al., 1998), but herbs are dilute natural drugs containing many different chemicals, and their effects may be unpredictable (Martin-Facklam et al., 2002). Few CAMs have been tested for side effects, quality control, or contamination. Some herbal medicines are toxic, interact with prescription drugs (Ernst, 1998; Wilkinson et al., 2002), cause surgical complications, or shorten survival time, indicating a need for greater doctor-patient communication (Richardson and Straus, 2002). The list of CAMs with purported cancer-fighting properties is growing rapidly, but few have been tested in rigorous clinical trials.

Our finding that CAM use followed from the recommendation of friends or relatives or mass media has been reported by others (Navo et al., 2004). As has been demonstrated many times, the mass media and non-government Web sites are not reliable sources of CAM

information (Navo et al., 2004), including information for cancer patients (Martin-Facklam et al., 2002; Spiegel et al., 1989).

Our finding that fewer than half the patients in our study discussed their use of CAM with their physicians is in agreement with studies done in Turkey (21.3%) (Tas et al., 2005) and Japan (39.3%) (Hyodo et al., 2005) but not in the U.S. (89.1%) (McEachrane-Gross et al., 2006). That few (1.6%) received recommendations for CAM use by their physicians is consistent with studies done in Japan (Hyodo et al., 2005) and Europe (Molassiotis et al., 2005), however it did not consistent according to geographic variance (Risberg et al., 2003). The reasons given in this study for patients' not communicating with physicians were the same as those reported in previous studies—the perception that physicians were indifferent to or opposed CAM use, the physicians' emphasis on scientific evidence, and anticipation of a negative response from the physician (Richardson, 1999; Tasaki et al., 2002). We found it curious that so few patients in our study discussed these practices with their physicians. That may be related to the fact that oncologists know little about CAM (Newell and Sanson-Fisher, 2000; Richardson, 1999) and underestimate their patients' use of it (Kao and Devine, 2000). Documentation and consultation about CAM use should become part of the routine assessment of cancer patients particularly for patients at the EOL. Several studies report that CAM users have less faith in physicians, feel abandoned by their physicians (Munstedt et al., 1996) and are less satisfied with conventional treatment.

Our multivariate analysis revealed a close association between CAM use and disease period length, primary cancer site, and medical or social supportive care, but not age or socioeconomic levels. Predictors of CAM in Western countries, however, include being female (Molassiotis et al., 2005; Risberg et al., 2003), younger (Burststein et al., 1999; Risberg et al., 2003), more highly educated (Kao and Devine, 2000; Lerner and Kennedy, 1992), employed (Verhoef et al., 2005), professional (Downer et al., 1994), and having a higher income (Kao and Devine, 2000; McEachrane-Gross et al., 2006), while other studies showed inconsistent associations (Navo et al., 2004) or none (Tasaki et al., 2002). Although several studies report no relationship between CAM use and conventional treatment (McEachrane-Gross et al., 2006), advanced stage (Tas et al., 2005), or disease site (Fernandez et al., 1998), patients with lymphoma or cancer of the brain or CNS tend to use CAMs. The stereotype that terminally ill, desperate, uneducated patients are the primary users of CAM is inaccurate (Lafferty et al., 2006).

Our finding that CAM use was associated with a longer disease period was reported previously (Sollner et al., 2000). An association of EOL CAM use with a need for medical or social supportive care is newly suggested in this study. Cancer patients may regard use of CAM as a way of actively and independently contributing to the

treatment of their disease. Higher interest in supportive care of patients using CAM could be as well motivated by perceived distress as by the tendency to actively coping the cancer and the active coping behavior associated with psychological adjustment to illness by reducing feelings of helplessness and hopelessness. However use of CAM was not always associated with lack of social support. Association with needs of supportive care and coping skill of patients and caregivers at the EOL should be evaluated in further study.

Our study had several limitations. First, the response rate was relatively low, so there was a potential for a bias introduced by a systematic difference between respondents and non-respondents. We used the IPTW estimator to avoid such a bias. Second, our study was performed by family proxies after the patients died, so there could have been recall bias (Verhoef et al., 2005).

In conclusion, our findings suggest that physicians should learn more about CAMs and candidly discuss CAM use with terminally ill cancer patients. That way, they would be able to inform them about contraindications and possible benefits, integrating CAM approaches that are beneficial or harm (Wall, 2003).

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